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# **Preventing violence, exploitation and abuse of persons with mental disabilities: Exploring the monitoring implications of Article 16 of the United Nations Convention on the Rights of Persons with Disabilities**

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## **Abstract**

Article 16 of the United Nations Convention on the Rights of Persons with Disabilities includes the right to be free from *all forms of violence, exploitation and abuse*. In pursuance of this aim, Article 16 (3) imposes an obligation on States Parties to ‘*ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities*’. Effective independent monitoring is viewed as a key mechanism to help safeguard people from violence, exploitation and abuse. This is highly pertinent in the wake of the highly publicized abuse of patients in care homes and hospitals in England in the last few years. This article will examine the monitoring requirements of Article 16 and, by drawing on the author’s research into the Care Quality Commission (the national health and social care regulator and mental health monitor) in England, assess the extent to which independent inspection of hospitals and care homes can play a part in realizing Article 16(3) to prevent violence, abuse and exploitation of persons with mental disabilities. The potential scope and reach of Article 16 is extremely wide: this brings with it great potential but, at the same time, significant challenges for achieving effective monitoring. Some of these challenges will be explored and the paper will conclude with some consideration of how monitors/inspectors, such as the Care Quality Commission in England, can strengthen their protection for people with mental disabilities, in line with the ethos and aspirations of the CRPD.

## **Keywords (7):**

Mental disability;  
violence,

abuse,  
exploitation;  
independent monitoring;  
CRPD;  
OPCAT.

## 1. INTRODUCTION

Over the last decade or so, the UK has witnessed a succession of horrific scandals relating to the abuse and ill-treatment of patients, particularly people with mental health and learning difficulties, by their care givers. For example, a public inquiry chaired by Sir Robert Francis QC in 2013 (the Francis Inquiry) found that hundreds of patients endured poor care and deficient treatment in Mid-Staffordshire hospital over a period of several years.<sup>1</sup> In a private learning disability unit, Winterbourne View in Bristol, residents were subjected to horrific and prolonged violence and abuse at the hands of support and care staff.<sup>2</sup> The tragic death of a young man with a learning disability, Connor Sparrowhawk, in a residential unit Dorset in 2013 due to the neglect of the staff is another shocking example. Connor died by drowning following an epileptic seizure while in the bath. Southern Health, the provider responsible for his care, accepted the serious failings in the care provided to Connor which contributed to his death.<sup>3</sup> The Care Quality Commission (CQC - the independent regulator of health and social care

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<sup>1</sup> *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry* (February 2013) HC 947 located at <http://webarchive.nationalarchives.gov.uk/20k150407084003/http://www.midstaffspublicinquiry.com/report>.

<sup>2</sup> NHS England (2014), *Winterbourne View: Time for Change* located at <https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf>.

<sup>3</sup> Located at <http://www.southernhealth.nhs.uk/news/archive/2016/trust-statement-regarding-connor-sparrowhawks-death/>.

in England) subsequently published a highly critical report on the unit where he died, finding that residents were still not being treated with respect or involved in discussions about their care and treatment.<sup>4</sup> As a result of Connor's death, in December 2016, the CQC published the findings of a review into all mental health and learning disability deaths in England, which confirmed that there is no single framework for National Health Service (NHS) trusts that sets out what they need to do to maximize the learning from deaths that may result from problems in care. The review was unable to identify any trusts that could demonstrate examples of good practice to ensure that learning is implemented. As a result, it concluded that '*learning from deaths is not being given enough consideration in the NHS and opportunities to improve care for future patients are being missed*'.<sup>5</sup> A report by the charity Mencap has recently concluded that these problems persist and there are still too many people with a learning disability living in similar units in the UK.<sup>6</sup> Indeed, more recently in November 2016, an undercover news report has highlighted the same failings in the care and ill-treatment of elderly and disabled residents at several nursing homes in Cornwall.<sup>7</sup>

These incidents have, unfortunately, been all too common and they are a sobering reminder of the increased vulnerability of people with mental disabilities,<sup>8</sup> particularly those who are living in residential units and hospitals. Traditional conceptions of abuse in institutions are rooted in Erving Goffman's model of the mental asylum – a 'total institution' - in which almost every aspect of the inmate/patient's life is controlled by

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<sup>4</sup> Located at [http://www.cqc.org.uk/sites/default/files/RW11V\\_Slade\\_House\\_INS1-1278665120\\_Responsive\\_-\\_Follow\\_Up\\_21-05-2014.pdf](http://www.cqc.org.uk/sites/default/files/RW11V_Slade_House_INS1-1278665120_Responsive_-_Follow_Up_21-05-2014.pdf).

<sup>5</sup> CQC (December 2016), *Learning, Candour and Accountability: A review of the way NHS Trusts review and investigate the deaths of patients in England* located at <http://www.cqc.org.uk/content/learning-candour-and-accountability>.

<sup>6</sup> Mencap (2014), *Winterbourne View: The Scandal Continues* located at [https://www.mencap.org.uk/sites/default/files/2016-08/Winterbourne\\_View\\_the\\_scandal\\_continues\\_0.pdf](https://www.mencap.org.uk/sites/default/files/2016-08/Winterbourne_View_the_scandal_continues_0.pdf).

<sup>7</sup> Located at <http://www.bbc.co.uk/programmes/b0844wq3> and the CQC response <http://www.cqc.org.uk/content/cqc-comment-panorama-nursing-homes-undercover>.

<sup>8</sup> The phrase 'persons with mental disabilities' is used here (in contrast to mentally disabled persons) in line with the terminology and approach adopted by the CRPD.

the institution.<sup>9</sup> People living in these institutions feel disempowered, degraded and depersonalized, and this occurs in both obvious and subtle ways. Their position and specific needs can make them more vulnerable to abuse, including physical, mental, financial/material as well as sexual abuse. Evidence suggests that people with mental disabilities are at increased risk of abuse, especially sexual abuse in institutional settings, which is 2-4 times higher than in the community.<sup>10</sup> However, it is not just a risk within institutions. With the changing patterns of care delivery and move towards community care since the 1960s, there is considerable evidence that similar abuses are widespread in the community, and disabled people suffer disproportionately higher levels of domestic abuse. This can come from partners, relatives, as well as personal carers/assistants and health/social care professionals. There is no doubt that the low status and pay of care givers, poor training/supervision as well as the challenging working conditions in the health and social care sector compound the risks. Chronic under-funding in the NHS and social care system in the UK puts staff and services under huge pressure, and consequently disabled people are placed in an even more vulnerable position.<sup>11</sup> Research by The Kings Fund in the UK has highlighted how care providers are struggling to retain staff and maintain the quality of care.<sup>12</sup> Many of the inquiries into the abuses in England mentioned above have also uncovered major

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<sup>9</sup> Goffman, E., (1961), *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*, New York: Anchor/Doubleday.

<sup>10</sup> Sobsey, D. and Mansell, S., (1990) The prevention of sexual abuse of people with developmental disabilities, *Developmental Disabilities Bulletin*, 18(2,) 51-66; Sobsey, D. and Mansell, S., (1994) Sexual abuse patterns of children with disabilities, *The International Journal of Children's Rights*, 2, 96-100; Sobsey, D. (1994), *Violence and Abuse in the Lives of People With Disabilities: The End of Silence Acceptance?*, Baltimore: Paul H Brookes Publishers.

<sup>11</sup> See for example The Kings Fund, *Is the NHS heading for financial crisis?* located at <https://www.kingsfund.org.uk/projects/verdict/nhs-heading-financial-crisis>; 'The state system to care for older and disabled people is under acute pressure and must be reformed', *The Observer*, December 2016 located at <https://www.theguardian.com/commentisfree/2016/dec/10/observer-editorial-government-must-increase-funding-social-care>. See also the very recent debate by MPs in the UK Parliament on the state of NHS and social care funding located at <http://www.parliament.uk/business/news/2017/january/mps-debate-nhs-and-social-care-funding/>.

<sup>12</sup> The Kings Fund (September 2016), *Social Care for Older People*. London.

systemic and management failures, many of which relate to the pressures placed on managers of balancing ever tightening budgets with demanding government targets.<sup>13</sup> This has led to a defensive culture in some parts of the NHS – ‘*concerned more with reputation, money and targets*’ rather than compassionate care, which should lie at the heart of the NHS.<sup>14</sup> As a result, there have also been significant cultural and attitudinal barriers to overcome in the UK, in particular for staff to feel confident about speaking up to voice patient care and safety concerns.<sup>15</sup>

It is commonly accepted that people with disabilities are more susceptible to violence/abuse/exploitation, as their impairment may create isolation, accessibility and dependence issues: ‘*Their reliance on care increases their situational vulnerability to other people’s controlling behavior and can exacerbate difficulties in leaving an abusive situation*’.<sup>16</sup> A World Health Organisation funded global review suggests that disabled adults are at a higher risk of violence than non-disabled adults and those with mental illness are particularly vulnerable.<sup>17</sup> In England, people with disabilities

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<sup>13</sup> See the findings of the Francis Inquiry into the failures of care at Mid-Staffordshire Hospital NHS Foundation Trust (*Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry* (February 2013) HC 947 located at <http://webarchive.nationalarchives.gov.uk/20150407084003/http://www.midstaffspublicinquiry.com/report>. The Inquiry found that mismanagement, staff shortages and under-funding contributed to the inadequate, inhumane and sub-standard care received by hundreds of patients between 2005-2009 in Mid-Staffordshire hospital.

<sup>14</sup> Department of Health (February 2015), *Culture Changes in the NHS: Applying the lessons of the Francis Inquiries Executive Summary*, Cm 9009, Para 5.1; located at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/403010/culture-change-nhs.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/403010/culture-change-nhs.pdf)

<sup>15</sup> See *Freedom to Speak Up: An independent review into creating and open honest reporting culture in the NHS* (February 2015) located at <http://freedomtospeakup.org.uk/the-report/>. See recent concerns about the operation and implementation of the whistleblowing (i.e. when employees report certain types of wrongdoing at work) processes in the NHS located at <https://www.opendemocracy.net/ournhs/minh-alexander-anonymous-pam-linton-clare-sardari/why-is-cqc-ignoring-or-even-suppressing-pri>; and recent media coverage “NHS’s first ‘national guardian’ resigns after two months”, *The Guardian* 8<sup>th</sup> March 2016 located at <https://www.theguardian.com/society/2016/mar/08/nhs-national-guardian-resigns-post-eileen-sills>

<sup>16</sup> Public Health England, (2015), *Disability and domestic abuse: Risks, impact and response* London: Public Health England, (p. 4).

<sup>17</sup> Hughes, K., Bellis, M. A., Jones, L. et al., (2012), Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies, *The Lancet*, 379 (9826), 1621-1629.

experience twice the rate of sexual assault, domestic abuse and stalking than non-disabled people.<sup>18</sup> There is no doubt that:

*‘The social context of disability, including factors such as inaccessibility, reliance on support services, poverty and isolation has a powerful impact on an individual’s increased risk of violence.’<sup>19</sup>*

People with mental disabilities can also be susceptible to exploitation, especially sexual in nature, due to their dependence on caregivers; emotional/ social insecurities and often lower levels of education regarding sexuality/ sexual abuse.<sup>20</sup> The increased risks to persons with disabilities have been well publicized and documented. Putting in place appropriate mechanisms to prevent such abuse is essential, yet presents challenges for national governments and authorities. The increased vulnerability of people with mental disabilities makes it more difficult for them to report abuse and less likely to be believed when they do disclose.

The Francis inquiry found that *effective* independent monitoring and regulation can play a part in promoting good standards of care and patient safety.<sup>21</sup> Following that inquiry as well as Winterbourne View, the CQC was urged to strengthen the way it uses its powers to take enforcement action to hold organizations to account for failing to

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<sup>18</sup> Public Health England, (2015), *Disability and domestic abuse: Risk, impacts and response*, London: Public Health England, (p. 9) located at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/480942/Disability\\_and\\_domestic\\_abuse\\_topic\\_overview\\_FINAL.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/480942/Disability_and_domestic_abuse_topic_overview_FINAL.pdf); Khalifeh, H. et al., (2013) *Violence against people with disability in England and Wales: findings from a national cross-sectional survey*, 8 PloS one.

<sup>19</sup> Powers, L. E. and Oschwald, M., *Violence and Abuse Against People with Disabilities: Experiences, Barriers and Prevention Strategies*, Center on Self-Determination, Oregon Health and Science University, (p. 2). [https://www.researchgate.net/publication/237835327\\_Violence\\_and\\_abuse\\_against\\_people\\_with\\_disabilities\\_Experiences\\_barriers\\_and\\_prevention\\_strategies](https://www.researchgate.net/publication/237835327_Violence_and_abuse_against_people_with_disabilities_Experiences_barriers_and_prevention_strategies).

<sup>20</sup> Regehr, C. and Glancy, G., (1995), Sexual Exploitation of Patients: Issues for Colleagues, *American Journal of Orthopsychiatry*, 65(2), 194-202; Public Health England op cit. pp. 11-12.

<sup>21</sup> *Report of the Mid-Staffordshire NHS Foundation Trust Inquiry* (February 2013) HC 947.

provide quality care.<sup>22</sup> The CQC is the independent health and social care regulator, established by s. 3(1) of the Health and Social Care Act 2008:

*‘...to protect and promote the health, safety and welfare of people who use health and social care services’.*

CQC therefore has a wide remit to inspect the range of health and social care services in England. It has an important role in safeguarding people who use these services in partnership with other agencies. There is a duty imposed on care providers to report any allegations of abuse/neglect to the CQC. CQC’s fundamental inspection standards expressly include safety (including safeguarding) as well as looking at whether services are caring, well led, effective and responsive to patient needs. In addition to this general regulatory duty, the CQC also has a statutory function to monitor those who are compulsory detained and treated under the mental health legislation in England. This responsibility includes meeting with patients and looking at the ward environment, privacy issues, medication/treatment and the use of restrictive practices. Moreover, in a similar vein, the CQC monitors patients who lack capacity and are deprived of their liberty in care homes/residential units under the Mental Capacity Act 2005.

Ensuring that monitors/inspection bodies such as the CQC are aware of all their international obligations is key, as they clearly do have an integral role to play in keeping service users safe and combating violence and abuse. In order that national monitors can play their part effectively, however, it is crucial for them to adopt appropriate and robust approaches to their inspection/ monitoring, which are reflective of and focused on the human rights of people with disabilities. Many inspection bodies in the UK, including the CQC, are already tasked with combating torture/inhuman/degrading treatment under the United Nations Optional Protocol to the Convention against Torture.<sup>23</sup> The OPCAT stipulates that National Preventive

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<sup>22</sup> Department of Health, (2012), *Transforming Care: A National Response to Winterbourne View Hospital*. London. See also NHS England, (2014), *Winterbourne View – Time for Change*, London and NHS England, (January 2015), *Transforming Care for People with Learning Disabilities – Next Steps*, London.

<sup>23</sup> The Care Quality Commission in England; Healthcare Inspectorate in Wales; the Scottish Mental Welfare Commission and the Regulatory and Quality Improvement Authority in Northern Ireland are all designated as National Preventive Mechanisms - national inspection



Mechanisms (NPM - i.e. designated national visiting /inspection bodies, of which the CQC is one) have a key preventive monitoring role. Detailed guidelines are provided to state signatories for NPMs by the Sub-Committee on the Prevention of Torture to promote independence, capability and a preventive focus in their monitoring work.<sup>24</sup> The guidance urges monitors to: have financial and operational autonomy; promote a 'preventive' approach by carrying out unannounced visits at all times; ensure a collective blend of relevant expertise and experience on inspection teams 'necessary for effective functioning'; meet privately with patients; as well as report on findings and follow-up on the implementation of recommendations. The OPCAT has undoubtedly made a significant impact in the context of the prevention of torture and ill-treatment. However, it is important not to view human rights treaties '*in isolation*' and '*recognize the interaction between the OPCAT and other mechanisms*'.<sup>25</sup>

The United Nations Convention on the Rights of Persons with Disabilities offers a further opportunity for NPMs to help to strengthen their protection for people with mental disabilities. Article 16 of the CRPD is clearly '*linked to the overall issue of prohibiting any form of cruel or inhuman or degrading treatment*'<sup>26</sup> (which is also prohibited in Article 15 of the CRPD), but it extends beyond the traditional OPCAT protection of those who may be deprived of their liberty.<sup>27</sup> Article 16(3) would seem to impose additional monitoring responsibility on national monitors (as organs of the state) to prevent these type of violations occurring to a much broader population of people with mental disabilities. In view of their existing OPCAT obligations to prevent torture and ill treatment, such monitors are potentially well placed to shoulder this additional responsibility, though it will require some expansion and modification to

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bodies - with responsibility for monitoring under OPCAT. Their inspection work and regulatory activity either includes or is focused on those who are deprived of their liberty under mental health/capacity legislation and/or using mental health/learning disability services.

<sup>24</sup> SPT (9 December 2010), *Guidelines on National Preventive Mechanisms*, CAT/OP/12/5, located at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CAT/OP/12/5&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT/OP/12/5&Lang=en).

<sup>25</sup> Murray, R. et al., (2010), *The Optional Protocol to the UN Convention against Torture*, Oxford: Oxford University Press. p. 181.

<sup>26</sup> Schulze, M., (September 2009), *Understanding the UN Convention on the Rights of Persons with Disabilities: A Handbook on the Human Rights of Persons with Disabilities*. Handicap International, (p. 71).

<sup>27</sup> <http://www.ohchr.org/EN/ProfessionalInterest/Pages/OPCAT.aspx>.

their mandates and approach, as well as financial commitment from national governments to provide adequate funding and resources to achieve that. The challenge will indeed be for NPMs to consider how they can monitor more widely beyond institutional abuse and ill-treatment.

A further link between the monitoring under the OPCAT and the CRPD is found in Article 33, which contains a general provision for national implementation and monitoring of the CRPD. It requires state parties to ‘*designate one or more focal points within government for matters relating to the implementation of the ...convention*’.<sup>28</sup> The precise relationship between the various monitoring mechanisms envisaged by the CRPD and their relationship with the OPCAT has still not been properly worked out however.<sup>29</sup> Until further consideration has been given to these issues by the SPT and CRPD Committee, we must consider and explore how state parties can implement the monitoring obligations of the convention. Article 16 has been relatively unexplored in the literature to date, and is, therefore, a good place to start.

This article will, first consider the nature and scope of Article 16 and specifically how it is likely to impact on the monitoring work of national inspection bodies. Secondly, it will examine some of the limits to the provision of ‘effective’ monitoring and protection under Article 16. Drawing on the work of the Care Quality Commission in England, the paper will conclude with some observations as to how independent monitors can help to realize the goals of Article 16 and promote the ethos of the CRPD for people with mental disabilities receiving care from health and social services.

## **2. The UN Convention on the Rights of Persons with Disabilities: A ‘Paradigm Shift’**

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<sup>28</sup> The Office for Disability Issues, a department within central government, has been designated as the focal point to co-ordinate the implementation of the CRPD across government in England and Wales. The ODI supports the development of policies to remove inequality between disabled and non-disabled people and published the first UK report on the implementation of the CRPD. However, it does not have any visiting/inspection functions, which means that national inspection/visiting bodies must play their part in helping to monitor and implement the CRPD - <https://www.gov.uk/government/organisations/office-for-disability-issues/about>.

<sup>29</sup> Murray, R., et al., (2010), *The Optional Protocol to the UN Convention against Torture*, Oxford: OUP. p 182.

The CRPD is an international treaty passed by the United Nations General Assembly in December 2006, which came into effect on 3<sup>rd</sup> May 2008. The Convention is intended to promote equality *for all people living with disabilities* as defined in Article 1: ‘*persons with disabilities include those who have long term physical, mental, intellectual or sensory impairments*’. The treaty adopts a broad conceptualization of disability as an ‘evolving’ concept, to include both long-term physical and mental impairments, including people with a mental illness, learning disability and psycho-social disabilities.

As charted elsewhere in this special issue,<sup>30</sup> the CRPD is revolutionary in re-conceptualizing rights specifically for people with disabilities. The ethos of the CRPD challenges the very core of what it is to be disabled and been described as heralding a ‘new era’ for people with disabilities.<sup>31</sup> It adopts the social model of disability, locating the barriers faced by disabled people within society rather than the person him/herself. Persons with disabilities are viewed as ‘subjects’ and not ‘objects of pity’.<sup>32</sup> This represents a sea change in the way that people with disabilities are viewed. The CRPD requires national governments (as convention signatories) to remove barriers and promote equality of treatment for all people with disabilities. The convention is underpinned by an ‘ideology of inclusion’<sup>33</sup> and its core principles promote, *inter alia*, autonomy, dignity, equality, non-discrimination and active participation of people with disabilities in all aspects of life. The focus of the treaty is therefore on putting people with disabilities at the centre of decision making relating to every aspect of their lives.

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<sup>30</sup> See for example Bartlett, P. and Schulze, M., (2017) Urgently Awaiting Implementation: The Right to be Free from Exploitation, Violence and Abuse in Article 16 of the Convention on the Rights of Persons with Disabilities (CRPD). *IJLP*, *Forthcoming*.

<sup>31</sup> Kofi Annan, ‘Secretary General hails adoption of landmark convention on rights of people with disabilities’ (13 December 2006) located at <http://www.un.org/press/en/2006/> accessed 23/12/2016. See also Lawson, A., (2008), The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?, *Syracuse Journal of International Law and Commerce*, 34, 563-619.

<sup>32</sup> In contrast to the medical model which locates the disability within the disabled person. This approach views disability as an impairment within the individual that requires treatment or intervention.

<sup>33</sup> Jones, M., (2005), Can international law improve mental health? Some thoughts on the proposed convention on the rights of persons with disabilities, *International Journal of Law and Psychiatry*, 28, 183-205, 186.

The treaty enshrines numerous rights for people with disabilities, including for example, positive rights to health care and education; as well as negative rights, such as the right to liberty and to be free from torture and ill treatment (in Article 15). Some of these rights are already promoted in other UN treaties, such as the OPCAT, but the CRPD is the first treaty which seeks to apply these rights specifically and directly to people with disabilities. As Kayess and French have argued, '*it seems clear that [the CRPD] has, in fact, modified, transformed and added to traditional human rights concepts in key respects' and transformed non-interference rights 'into positive state obligations'*'.<sup>34</sup> Significantly therefore, Article 16 implies a *positive obligation* on state parties to provide independent mechanisms to prevent violence, abuse and exploitation as does the OPCAT. Moreover, the CRPD protection extends beyond those who are in the custody of the state. The treaty has been signed and ratified by the UK government and provides a real opportunity to bolster the rights of people with disabilities.

There is no doubt that the treaty brings with it significant 'promise', however, some commentators have been cautious about its implementation, as it also brings with it many challenges and '*requires a radical reappraisal of society's approach to human rights protection'*'.<sup>35</sup> One of the biggest obstacles in the UK is the fact that, due to the doctrine of duality in international law, it is not directly enforceable in the national courts. The UN CRPD Committee has recently conducted an inquiry into the impact of the UK government's welfare reforms on people with disabilities. In its report, the Committee pointed out:

*The State party's Government considers the Convention as being part of the main framework for the protection of persons with disabilities together with the Equality Act 2010, which addresses situations of discrimination and establishes the public sector equality duty.... It also acknowledges the Convention as a key piece of legislation that sets out what governments should do to promote and protect the rights of persons with disabilities. Its Parliament has highlighted*

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<sup>34</sup> Kayess, R. and French, P., (2008), Out of Darkness and into Light? Introducing the Convention on the Rights of Persons with Disabilities, *Human Rights Law Review*, 8, 1.

<sup>35</sup> Bartlett, P., (2012), The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law, *Modern Law Review*, 75(5), 752-778, 752.

*that the Convention and other human rights international instruments are binding obligations in international law and therefore the State party should give them adequate consideration in decision-making processes. However, the Convention has not been incorporated into domestic law and is still not directly justiciable.*<sup>36</sup>

Despite this, it is encouraging to note that the CRPD has already been influential in a persuasive manner in a national context in the UK. For example, in *London Borough of Haringey v Lush*<sup>37</sup> the judge expressed the view that: ‘*Although it does not form part of our domestic law, it may have an interpretative influence, particularly in cases affecting the rights of a person with a disability.*’ There are some promising signs that the CRPD is beginning to exert some influence on the development of law and policy in the UK and is featuring more prominently in the jurisprudence of the national courts.<sup>38</sup>

Nevertheless, the CRPD Committee report was critical of the UK government’s recent welfare policy and the extent to which various measures have ‘*disproportionately and adversely affected the rights of persons with disabilities*’.<sup>39</sup> It is clear from the report that there are responsibilities on the national government and all state actors to take

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<sup>36</sup> *Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention: Report of the Committee* located at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2f15%2fR.2%2fRev.1&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2f15%2fR.2%2fRev.1&Lang=en).

<sup>37</sup> [2014] EWCOP B23.

<sup>38</sup> See for example the Law Commission in England and Wales’ comments in its recent consultation paper on (2016) *Mental Capacity and Deprivation of Liberty Consultation Paper No 222*. London at para. 3.22: ‘*The UN Disability Convention challenges existing understandings and categorisations of disability rights. There is much in its terms to be enthusiastic about. Its full implications are still being grappled with by governments across the world. In our new scheme we have attempted to avoid unduly rigid reading of the UN Disability Convention. .... our new scheme aims to support the principles of the UN Disability Convention, whilst creating an appropriate balance with the existing regime of the Mental Capacity Act and ensuring compatibility with the European Convention on Human Rights*’ located at <http://www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/>.

<sup>39</sup> *Ibid.* para. 113(d).

steps to comply with the convention. To fully realize the rights enshrined in the CRPD and promote its enabling ethos, there is a need to promote action and implementation *by all organisations and individuals involved with disabled people*, not just the judiciary and government/ public bodies. As Don Mackay, the Chair of the Committee that negotiated the Convention stated, national governments ‘*cannot simply sit on their hands and decide to do nothing*’ and ‘*[e]ffective implementation will now be the key*’.<sup>40</sup> This will only be fully realized if national monitoring bodies, such as the CQC in England, are aware of their Article 16 CRPD obligations in Article 16(3) and promote them on a routine and regular basis in their inspection work. To give effect to the Convention and reflect its principles means engaging directly with people with mental disabilities and putting them at the heart of approaches to inspection/monitoring. This means helping to empower and support individuals with a mental disability to voice concerns/speak out. It means removing barriers, by putting accessible support and complaint systems in place to enable people with mental disabilities to be safe. The following sections will explore the scope of Article 16 and identify how national monitors can adopt strategies which promote this empowering ethos of the CRPD for this ‘at risk’ group.<sup>41</sup>

### **3. Article 16: opportunities and challenges**

- ‘*To prevent the occurrence of all forms of exploitation, violence and abuse*’

If we start by looking at the nature of the protection, the extremely broad reach of Article 16 imposes heavy obligations on state parties to take appropriate measures to prevent ‘*all forms*’ of exploitation, violence and abuse. This covers a wide range of violations and has the potential to bolster some of the greatest threats to people with mental disabilities. The concepts of violence, abuse and exploitation are clearly linked to but distinct from torture/inhuman/degrading treatment in the UN Convention against Torture (CAT). The definition of torture in the CAT (Article 1(1)) is limited to the intentional infliction of physical/mental harm, though Article 16 of the CAT makes it

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<sup>40</sup> Mackay, D.. (2008), The United Nations Convention on the Rights of Persons with Disabilities, *Syracuse International Journal of Law and Commerce*, 34, 323-330.

<sup>41</sup> Bartlett, P., op cit., p. 759.

clear that other unintentional forms of ill-treatment, including inhuman/degrading treatment, are also subject to the same preventive obligation.<sup>42</sup> There is clearly considerable overlap between these concepts, which suggests that NPMs are well suited to carry out the task in hand under Article 16(3). Though Article 16 of the CRPD embraces a wider range of subtler, lighter and/or isolated forms of harm, as there is no need for it to reach a particular intensity, as required under Article 3 of the European Convention on Human Rights.<sup>43</sup> In that sense, the scope of the preventive monitoring function of the NPM is much broader than the narrower focus of inhuman treatment under Article 3.

The concepts found in Article 16 are not novel and do feature in other international human rights treaties. For example, Article 19(1) of Convention on the Rights of the Child contains similar protection from violence against children. In its General Comment No. 13, the Committee on the Rights of the Child made it clear that violence is defined broadly to represent all forms of harm to children, including neglect; mental and physical violence; sexual abuse and exploitation; torture/inhuman treatment; and self-harm.<sup>44</sup> The terms are not defined anywhere in the CRPD and there is not yet any guidance/comment on Article 16 from the CRPD Committee. Much is therefore left to interpretation by state parties. The concepts are undoubtedly expansive and all-encompassing. To give effect to the spirit of the CRPD would suggest they should be

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<sup>42</sup> Murray, R. et al., (2011), *The Optional Protocol to the UN Convention Against Torture*, Oxford: Oxford University Press, p. 59. Not also that the concept of inhuman treatment under Article 3 of the European Convention on Human Rights (ECHR) covers an equally wide spectrum of ill-treatment and punishment as the European Court of Human Rights case law demonstrates, although it is required to reach a minimum level of severity – see *The Greek case* ((1969) (Commission Report, 5 November 1969); *Ireland v United Kingdom* (1978) Appl. No. 25760/94, 17 February 2004.

<sup>43</sup> Note that the CRC in its General Comment No 13 (*The right of the child to freedom from all forms of violence* CRC/C/GC13) has taken the view that ‘*all forms of violence against children, however light, are unacceptable*’ in Article 19(1) of the Convention on the Rights of the Child (at para. 17). Arguably, the CRPD Committee would be keen to adopt an equally expansive approach to ensure maximum protection for people with disabilities.

<sup>44</sup> CRC, (April 2011), *The right of the child to freedom from all forms of violence*, CRC/C/GC/13 located at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fGC%2f13&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC%2fC%2fGC%2f13&Lang=en)

given an equally broad and purposive definition, in line with the expansive definitions in the CRC.

The concepts are inherently subjective – thereby rendering them very difficult to define and identify. Indeed, they have been described as ‘*amorphous*’ by one commentator.<sup>45</sup> However, this may not present too great a challenge for NPMs due to the preventive nature of their role, which makes questions about ‘severity’ essentially redundant. The concepts are also relative, and Article 16(3) does explicitly recognize their gender and age based aspects. Research in the UK and US has demonstrated that women, especially those who are disabled, are at an increased risk of domestic violence and abuse.<sup>46</sup> The increased vulnerability of young people with disabilities to domestic and other abuse has also been documented.<sup>47</sup> National monitors must be mindful of these complexities and develop standards and approaches which are sensitive to age and gender but also to cultural, religious and social dimensions<sup>48</sup> in their monitoring work.

However, an added complication is that there may be differences in understanding between professional groups about the identification of risks of abuse and appropriate responses to it. Many clinicians working with disabled patients/service users are still

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<sup>45</sup> Megret, F., (2008), The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights? *Human Rights Quarterly*, 30(2), 494-516, 508.

<sup>46</sup> Hague, G. et al., (2011), Disabled women, Domestic Violence and Social Care: This Risk of isolation, vulnerability and neglect, *British Journal of Social Work*, 41, 148-165; Radford J. et al (2006), Disabled women and domestic violence as violent crime in practice, *Journal of the British Association of Social Workers*, 18(4), 233–468; Dixon, J. and Robb, M., (2016), Working with Women with a Learning Disability Experiencing Domestic Abuse: How Social Workers can Negotiate Competing Definitions of Risk, *British Journal of Social Work*, 46, 773-788; Nosek, M. et al., (2011), Vulnerabilities for abuse among women with disabilities’, *Sexuality and Disability*, 19(3), 177–90.

<sup>47</sup> Balogh, R. et al (2001), Sexual Abuse in Children and Adolescents with Intellectual Disability, *Journal of Intellectual Disability Research*, 45(3), 194-201.

<sup>48</sup> Cultural, religious and sexual /gender identity issues may compound risk and vulnerability for a disabled person – but the intersection is often overlooked by practitioners– see Public Health England op cit. p. 7. See also for example NSPCC, (June 2014), *Culture and Faith: Learning from Case Reviews* located at <https://www.nspcc.org.uk/preventing-abuse/child-protection-system/case-reviews/learning/culture-faith/>.



guided by the medical model,<sup>49</sup> which is narrower in focus than the social approach, as it tends to view disability as an individual issue. In contrast, other professional groups, such as social workers and those working in community psychiatric teams for example, will be more sympathetic to the social model, in line with the philosophy of the CRPD.<sup>50</sup> Inspectors/visiting bodies must therefore take steps to promote awareness, develop clear standards and unified approaches to guide inspectors and care/service providers. Adopting a multi-disciplinary approach to training programmes and inspections will also help to align professional knowledge and understanding.<sup>51</sup>

Finally, it should be noted that the focus in Article 16 is on *prevention* rather than protection. In the context of the OPCAT, the concept of prevention as opposed to protection has given rise to some debate.<sup>52</sup> One commentator suggested that there is very little difference between the two and that '*prevention is protection by another name*'.<sup>53</sup> However, others maintain that '*prevention*' is broader and '*casts a wide net*'. It would include such matters as education and training '*which have a clear preventive nexus*'.<sup>54</sup> In which case, it would greatly assist monitors in their role if the CRPD Committee adopted a similar approach to the SPT<sup>55</sup> in terms of providing practical guidance and principles to assist with the Article 16 monitoring functions. The CRPD Committee has a key role in monitoring implementation of the convention by state parties and can issue general comments to aid interpretation and implementation.<sup>56</sup> It

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<sup>49</sup> See for example Bricher, G., (2000), Disabled People, Health Professionals and the Social Model of Disability: can there be a research relationship? *Disability and Society*, 15(5), 781-793.

<sup>50</sup> Public Health England op cit p. 6; Hague, G. et al., (2011), Disabled women, Domestic Violence and Social Care: This Risk of isolation, vulnerability and neglect, *British Journal of Social Work*, 41, 148-165.

<sup>51</sup> It has been reported that appropriate joint training on disability and domestic abuse can be effective and significantly improve professional attitudes and knowledge. See Bowman, R. et al, (2010), Sexual abuse prevention: A training program for developmental disabilities service providers, *Journal of Child Sexual Abuse*, 19, 119-127.

<sup>52</sup> Murray, R. et al (2011), *The Optional Protocol to the Convention Against Torture*, Oxford: OUP, p. 62.

<sup>53</sup> Rodley, N. (2010), Reflections on Working for the Prevention of Torture, *Essex Human Rights Review*, 6(1), 21 at p. 29.

<sup>54</sup> Murray, R. et al (2011), *op cit* p. 62.

<sup>55</sup> Ibid. p. 175.

<sup>56</sup> See <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx>.

has already published several comments on other articles of the convention and there is undoubtedly a need to clarify some of the ambiguities about the potential reach of Article 16. This would encourage national monitors to develop clear standards and guidelines to help educate practitioners on the identification of, as well as consistent and appropriate responses to abuse, violence and exploitation against persons with mental disabilities.

- ‘*All facilities and programmes designed to serve persons with disabilities*’

Notably, Article 16(3) extends independent monitoring to *all facilities and programmes* designed for persons with disabilities. There is clear recognition here of the potential for increased vulnerability and powerlessness of *all* people with mental disabilities, not just those who are detained or living in institutions. As previously stated, NPMs already have an obligation to give effect to the OPCAT in their monitoring methodology and focus on ill-treatment and torture prevention in places of detention. OPCAT’s reach is potentially broad in one sense, as it includes *all facilities where people may be detained*, such as prisons, immigration centres, police stations, mental institutions and care homes. However, its remit is narrower than the CRPD, as it is focused only on places where people may be detained or deprived of their liberty. The remit of the CRPD is much broader to embrace all persons with mental disabilities, whether they are deprived of their liberty or not. Moreover, the protection extends beyond facilities (i.e. units; homes; hospitals) to monitoring *all programmes*. This term is not defined in the treaty, but presumably embraces any community based/social services which are provided /made available to people with mental disabilities. This accepts the broader social context and range of circumstances within which abuse may also occur, however, its open-ended nature will present immense practical and logistical issues for monitoring all these types of situations and will vastly increase the potential population subject to oversight and monitoring.

The Care Quality Commission in England is fortunate in that it does already have jurisdiction to visit a wide range of health and social care institutions, including mental health and learning disability facilities. The CQC also regulates and inspects a range of other health care services in the NHS, for example, dental and ambulance services. In that respect, it is well placed to ensure reasonably broad coverage for Article 16. But it

does not have a remit beyond the publicly funded health and social care sector. There are obvious difficulties to detecting and monitoring abuse in the broad range of contexts envisaged by Article 16 and this makes it very difficult for state protection. Violations may well be beyond the reach of traditional and established inspection/monitoring bodies, whose mandates are often limited to inspecting public institutions. Governments will therefore need to consider both if and how visiting mandates can be refocused to ensure that they have sufficient reach. And, of course, this should also be accompanied by appropriate resources, both financial and human, to enable inspectors to fulfil any additional CRPD-related monitoring work. But this may be one of the biggest challenges, particularly in an English context for the CQC, which has been dogged by concerns about the breadth of its remit and the inadequate resources it has been given to successfully achieve its inspection and regulatory functions.<sup>57</sup> A report by the House of Commons Public Accounts Committee into the CQC in December 2015 expressed concerns about the staffing levels at the organization and questioned how it would be able to ‘deliver its programme of inspections in the face of substantial funding reductions’.<sup>58</sup> It is however vital for national governments, including the Department of Health in England, to recognize that there is always a risk of abuse when caregivers are in a position of power/control over mentally disabled people, including those living in the community and receiving personalized care in their own homes, and commit to providing sufficient human and financial resources to enable monitors to provide effective protection in line with the requirements of Article 16.<sup>59</sup>

- ‘*Within and Outside the Home*’

Indeed, Article 16 covers both abuses that occur within the public sphere ‘outside’ the home *and* also in private - ‘within the home’. This is highly significant. As Megret has acknowledged, it is novel and extends the reach of international human rights law ‘*beyond the limited realm of the state’s relationship to individuals within its*

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<sup>57</sup> See for example the extensive criticisms of the CQC by the Francis Inquiry into the failures of care in Mid-Staffordshire cited above (op cit).

<sup>58</sup> *Twelfth Report of Session 2015-16- Care Quality Commission* HC 501 (11 December 2015) p. 5.

<sup>59</sup> Equality and Human Rights Commission (2011), *Inquiry into older people and human rights in home care*, London; Powers L. E. and Oschwald M., op cit. pp. 5-6.

*jurisdiction.*<sup>60</sup> However, it undeniably presents huge challenges for traditional monitoring bodies such as the CQC, as their remit is limited to monitoring care in ‘publicly’ funded services and/or institutions. In England, the CQC’s remit does not extend to privately-funded home care or supported living accommodation. Responsibility for monitoring and oversight of home care provision often falls through the gaps. A recent inquiry into human rights in home care in the UK found that legal safeguards in private homes, such as those found in the ECHR/Human Rights Act 1998 (HRA), are not as widely used as they should be.<sup>61</sup> Moreover, the protection afforded by the HRA does not extend to most people (often elderly and/or disabled) who receive care at home, as it may be self-funded or delivered by a private or voluntary sector organization. This is a worrying loophole as research suggests that older people and those with disabilities are especially vulnerable to economic abuse by home care providers.<sup>62</sup> State parties to the CRPD, including the government in England, must therefore consider to what extent they can effectively discharge their monitoring obligations under Article 16 by extending the reach of some form of oversight to the provision of all services in private homes/living accommodation. Embracing this type of approach however, which could imply state-sponsored inspection within people’s own homes, would be contentious and a potentially unwelcome encroachment on individual liberty, as highlighted further in the discussion below on the inherent tensions in Article 16.

- *Inherent tensions*

One of the most discernable challenges to effective implementation of Article 16 is working out how to address abuse and protect persons with mental disabilities without limiting their autonomy and control. As other papers in this special issue have identified,<sup>63</sup> the protectionist approach suggested by Article 16 seems incompatible

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<sup>60</sup> Megret F., op cit. p. 508

<sup>61</sup> Equality and Human Rights Commission (2011), *Inquiry into older people and human rights in home care*. London.

<sup>62</sup> Powers, L. E. and Oschwald, M., op cit. pp. 5-6.

<sup>63</sup> See for example Bartlett P. and Schulze, M., (2017) Urgently Awaiting Implementation: The Right to be Free from Exploitation, Violence and Abuse in Article 16 of the Convention on the Rights of Persons with Disabilities (CRPD). *IJLP, Forthcoming*; Fallon-Kund, M. Coenen, M.

with the ethos of autonomy and empowerment in the CRPD. As Bartlett rightly questioned writing about the CRPD in 2012:

*‘does [article 16] provide a role for proactive state intervention of a sort that a person with disability may sometimes view as coercive’?*<sup>64</sup>

The CRPD itself does not address this issue, and neither has the CRPD Committee, but other contributors to this special issue have attempted to reconcile the two.<sup>65</sup> Whilst monitors/inspection bodies are not directly involved in taking action to remove individuals from an abusive or violent situation, they can nevertheless exert considerable influence on service/care providers by making recommendations for change and reduce or eliminate some of the risks. Some inspection bodies, such as the CQC, can take enforcement action against providers, such as issuing conditions and warning notices. In serious cases, CQC has the power to use a range of criminal and civil sanctions to prosecute, including an offence of willful neglect for individuals who deliberately allow patients to suffer harm. Whilst these powers to compel providers to improve the standards of quality of care are an important tool in their armory, monitors must also be mindful of the tension in Article 16. It must be borne in mind through monitoring and enforcement /remediation strategies, that the ‘trauma of change’ may be viewed as unwelcome and do more harm than good for some vulnerable people with mental disabilities.<sup>66</sup> Achieving the right balance between protection and personal autonomy/control is extremely challenging, but key to promoting the aims of the convention.

- *Perceptions of care*

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and Bickenbach, J., (2017) Balancing autonomy and protection: a qualitative analysis of court hearings dealing with protective measures. *IJLP, Forthcoming*.

<sup>64</sup> Bartlett, P., op cit. pp. 759-760.

<sup>65</sup> See for example Keeling, A., ‘Organising Objects’: Adult Safeguarding Practice and Article 16 of the United Nations Convention on the Rights of Persons with Disabilities (2017) *IJLP Forthcoming*.

<sup>66</sup> Connolly, M-T. (2008), Elder Self-neglect and the Justice system: An essay from an interdisciplinary perspective, *Journal of the American Geriatric Society*, 52(56), S244-S252, S245.

Another potential inhibitor to providing effective protection under Article 16 may be public/service user perceptions of the quality of care, particularly in homes/hospitals, which has of course been exacerbated recently in the UK by the number of national and high-profile care scandals. The knock-on effect may be that those in need may prefer to endure all kinds of suffering at home, rather than accept institutional care and support:

*‘If people who need care would rather die than go to a facility to obtain that care, imagine what hardships they are willing to endure as an alternative to going to a facility... perceptions of quality problems in long-term care... cause countless ... people to remain in environments where they neglect themselves (or are at risk for other reasons)’.<sup>67</sup>*

A recent case in England where an elderly man attacked his 88-year-old wife in an attempt at a ‘mercy killing’, as she had begged him to take her life and not allow her die in a care home is a shocking example of the alternative risks/consequences that some old people and those with a disability are prepared to face.<sup>68</sup>

National government and inspectors/monitors such as the CQC should therefore ensure that successes are celebrated and examples of good practice are widely publicized, to try to counteract some of these concerns and (mis)conceptions. The CQC is now taking (small) steps to disseminate examples of good practice and improve perceptions of the quality of care.<sup>69</sup> It makes this type of information available on its website and attempts via media outlets, including social media, to inform the public about outstanding/good ratings and involve it more directly in its inspection findings.<sup>70</sup> Additionally, it publishes guidance to inspectors and information for providers and the public on its

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<sup>67</sup> Ibid. p. S246.

<sup>68</sup> See <https://www.theguardian.com/uk-news/2017/apr/25/denver-beddows-95-mercy-killing>.

<sup>69</sup> See for example CQC (May 2015), *Mental Health Bulletin*; CQC (July 2015), *Celebrating Good Care, Championing Outstanding Care*. London.

<sup>70</sup> See for example <http://www.cqc.org.uk/content/examples-outstanding-practice-gps>; and <http://www.cqc.org.uk/content/cqc-publishes-examples-outstanding-practice-new-online-toolkit-gps>.

*Human Rights Approach* to inspection.<sup>71</sup> However, research has revealed that there is still limited awareness of and engagement with international human rights standards/obligations, such as the CRPD, among front-line inspectors and health care professionals.<sup>72</sup> This is compounded by poor awareness/understanding among staff/practitioners of key legislation, for example mental health and capacity legislation in England, which is also a barrier to good practice and patient empowerment /capacity building.<sup>73</sup>

- *Perceptions of monitors and promoting independence*

Maintaining public confidence and credibility in the national monitoring mechanisms is also key. People may well be disinclined or discouraged from speaking up if they feel that the regulator/inspector is ineffective or powerless. Monitors must therefore adopt affirmative and proactive measures to reassure the public and patients about their work. Again, the CQC seeks to do this through a range of media formats and proactively encourages the public to get involved in regular consultations. This is generally via the CQC website. There is a need however to ensure that consultation time limits are flexible and information is made available in a range of accessible formats, to enable people with mental disabilities to actively engage with and participate meaningfully in these processes.

Public (re)assurance and confidence is also integral from the perspective of promoting the ‘independence’ and accountability of the inspection body, in line with Article 16(3). As outlined above, the OPCAT already requires independent monitoring and the SPT guidance expands on this in terms of recommending financial and operational autonomy for NPMs. Arguably, the same would be expected for any independent monitoring mechanism under the CRPD.<sup>74</sup>

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<sup>71</sup> See <http://www.cqc.org.uk/content/equality-and-human-rights-guidance-our-inspectors-0> and <http://www.cqc.org.uk/content/our-human-rights-approach>.

<sup>72</sup> Laing J.M., (2014) Perspectives on Monitoring Mental Health Legislation in England: A view from the front line, *Medical Law Review*, 23 (3), 400-426.

<sup>73</sup> Department of Health (July 2013), *Confidential Inquiry into Premature Deaths of People with Learning Disability*.

<sup>74</sup> Note that Article 18(4) OPCAT states that ‘national preventive mechanisms... shall give due consideration to the Principles relating to the status of national institutions for the promotion and protection of human rights’ and, similarly, Article 33(2) of the CRPD states that

In England, the CQC has faced an uphill struggle in terms of securing credibility and confidence. Healthwatch England, as the consumer champion for health and social care in England, examined the public's experiences of the health and social care complaints system in 2014. The survey found that people do not have confidence or trust in the current systems for making complaints, which includes raising concerns with the CQC.<sup>75</sup> Negative perceptions of the CQC have undoubtedly been compounded in the recent past, as it has faced widespread condemnation, particularly in the wake of Winterbourne View and the Francis inquiry.<sup>76</sup> In response, the organization implemented a variety of measures to reform and refocus its monitoring strategy, in an attempt to rebuild public trust and confidence.<sup>77</sup> A recent Department of Health review of progress since the Francis inquiry stated that:

‘Re-establishing the credibility and effectiveness of the Care Quality Commission has therefore been a critical component of the Government response to the Inquiry, seeking to establish the regulator as a trusted, authoritative and independent agency that can quickly identify poor care so that

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*‘independent mechanisms...shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights’.* The principles referred to here include the ‘Paris Principles’, which were adopted by the United Nations General Assembly in December 1993. The Principles set out the key features of national human rights institutions and provide that: the national institution must have competence to promote and protect human rights; as broad a mandate as possible; its independence must be established by statute/ constitution and it must be adequately funded *‘in order to be independent of the Government and not be subject to financial control which might affect its independence’*. See further de Beco G. and Murray R. (2014), *A commentary on the Paris Principles on National Human Rights Institutions*. Cambridge: Cambridge University Press.

<sup>75</sup> Healthwatch England op cit p. 23-27.

<sup>76</sup> See for example, House of Commons Public Accounts Committee Report op cit p.3 ; ‘Care Quality Commission not yet an effective regulator says MPs’ located at <http://www.bbc.co.uk/news/health-35062503>; ‘Care Quality Commission problems – timeline’, *The Guardian*, 23 February 2012 located at <https://www.theguardian.com/politics/2012/feb/23/care-quality-commission-problems-timeline>; BMA, ‘Doctors declare CQC not fit for purpose’, 30 June 2016 located at <https://www.bma.org.uk/news/2013/june/doctors-declare-cqc-not-fit-for-purpose>.

<sup>77</sup> ‘It is important that our staff are trained and supported to carry out high-quality inspections, which result in robust judgements that the public can have confidence in. Our business plan sets out a revised timetable for our planned inspections to help us do this.’ ‘CQC sets priorities for 2015/16 and ambitions for the future of regulation’ (27 March 2015) located at <http://www.cqc.org.uk/content/cqc-sets-priorities-201516-and-ambitions-future-regulation>.



effective action can be taken. The Care Quality Commission has a new Chair, a new Chief Executive and a new board. Three powerful and independent Chief Inspectors have been appointed, covering hospitals, general practice and adult social care. The organisation's independence has been strengthened in legislation. The Care Quality Commission's inspection model has been completely overhauled, moving from a generalist light-touch and tick-box model to a thorough approach, informed by experts, patients and staff.<sup>78</sup>

The Parliamentary Public Accounts Committee recognized in 2015 that the CQC '*has made substantial progress since the Committee last reported in 2012*', but concluded that there is still a long way to go, as it is still '*behind where it should be... and not meeting the trajectory it set itself*'.<sup>79</sup> There is also a question mark about the degree of both financial and operational independence enjoyed by the organization.<sup>80</sup> It is part-funded by central government and can be required to conduct special reviews at the request of the Secretary of State for Health, for example, the recent review into mental health and learning disability deaths noted earlier. Moreover, care providers part-fund the cost of regulation through payment of care provider fees to the CQC.<sup>81</sup> This may also compromise its ability to exercise a truly independent inspection function, in the same way as other regulators in England, for example the Human Fertilization and Embryology Authority, has been criticized in the past for receiving an increasing share of its revenue through licensing fees from fertility clinics.<sup>82</sup>

It is notable that Article 16(3) has been criticized for not additionally requiring 'competency' on the part of the monitoring mechanism(s).<sup>83</sup> As the SPT has recognized in its guidelines, NPMs must have sufficient budget, staff, expertise and autonomy to

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<sup>78</sup> Department of Health (February 2015), *Culture Change in the NHS: Applying the lessons of the Francis Inquiries Executive Summary*, Cm 9009, para. 5.

<sup>79</sup> See Public Accounts Committee (11 December 2015), *Twelfth Report – Care Quality Commission*, HC 501, located at <http://www.publications.parliament.uk/pa/cm201516/cmselect/cmpubacc/501/50102.htm>

<sup>80</sup> Laing J.M., op cit. This may not comply with the Paris Principles requiring financial autonomy from the State. See n. 74.

<sup>81</sup> See for example 'Care providers have to pay too much for regulation. CQC must step up', *The Guardian*, 10 March 2016 located at <https://www.theguardian.com/social-care-network/2016/mar/10/care-quality-commission-cqc-inspection-fees>.

<sup>82</sup> See for example, Singer, D. and Hunter, M., (Eds.), (2003) *Assisted Human Reproduction: Psychological and Ethical Dilemmas* (Whurr Publishers) p. 20.

<sup>83</sup> Schulze, M., op cit. p. 73.

‘provide effective functioning’ and fulfil their mandate.<sup>84</sup> These must also be essential components to providing effective, independent and preventive CRPD-related monitoring systems and would be in line with the requirements of the United Nations Paris Principles for national human rights institutions.<sup>85</sup>

- *Detection and reporting mechanisms*

There remain other significant challenges to reporting and detecting violence/abuse/exploitation, which further impede effective monitoring and inspection. People with learning and other related disabilities are not always forthcoming about reporting instances of abuse for a variety of reasons.<sup>86</sup> Patients/ service users with mental disabilities may be worried that they will not be believed as they have traditionally not been regarded as reliable reporters. There are also potential communication problems, particularly when capacity is compromised, and there may be embarrassment/shame about disclosure, coupled with the fear of backlash. Typically, mentally disabled patients do not question caregivers or others in authority. There are also evidential difficulties in terms of identifying and proving subtler forms of abusive/neglectful behavior. Finally, there may well be fear that professional services do not take concerns seriously and that reporting abuse may lead to disempowerment, intrusions and disregard for privacy or loss of independence. The Healthwatch England study mentioned above found that members of the public often do not complain because they are ‘*scared of the repercussions, such as being victimized by staff*’.<sup>87</sup> In particular, patients treated under mental health or capacity legislation ‘*feared retribution from staff, or a decline in the quality of their treatment*’ if they raise concerns.<sup>88</sup> Similar sentiments were also often expressed by patients in the Francis inquiry. A report into human rights abuses in home care in England by the Equality

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<sup>84</sup> See SPT, op cit.

<sup>85</sup> The Principles stipulate that, *inter alia*, national institutions must be vested with competence to promote and protect human rights and be given as broad a mandate as possible’. See n. 74.

<sup>86</sup> Powers, L. E. and Oschwald, M. op cit., pp. 7-9; Connolly, M-T., op cit. pp. S245-S246; Public Health England op cit.

<sup>87</sup> Healthwatch England (November 2013), *Improving the health and social care complaint systems: A position statement and briefing*, p. 3. Located at [http://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/health\\_and\\_social\\_care\\_complaints\\_systems.pdf](http://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/health_and_social_care_complaints_systems.pdf).

<sup>88</sup> Ibid. p. 24.

and Human Rights Commission found that older people were reluctant to make complaints as they did not want to get their care workers into trouble, did not want to make a fuss or feared being put into residential care.<sup>89</sup>

People with mental disabilities must be encouraged, facilitated and supported to raise concerns and complaints with monitors. However, there is evidence in England that many of the procedures for raising concerns/complaints about health /social care are cumbersome and not always working effectively.<sup>90</sup> A review of NHS hospitals complaints in 2013 found major weaknesses in the system, including lack of information on complaint systems; cumbersome, insensitive and unresponsive processes and fears from complainants of professional intimidation or backlash.<sup>91</sup> People may lack awareness of the appropriate standards, especially for home care and the complaints processes are often complex/unclear or not well understood. For example, in the context of a complaint about mental health care/treatment, patients who are compulsorily detained under mental health legislation may complain to the CQC, however, voluntary/informal patients are unable to do so. Alternatively, complaints about the standards of health care or staff behaviour in the NHS can be channeled through the NHS complaints procedures; to professional regulatory bodies such as the General Medical Council/ Nursing and Midwifery Council or to the Parliamentary Health Ombudsman. Patients are often encouraged to seek local resolution first before resorting to any of the national regulators, ombudsmen or authorities. The result is a complex web of complaints mechanisms which are difficult to locate and navigate, especially so for individuals with limited mental capacity and/or a learning disability.

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<sup>89</sup> Equality and Human Rights Commission (2011), *Inquiry into older people and human rights in home care* (London) p. 7.

<sup>90</sup> See for example CQC (December 2014), *Complaints Matter*, located at [http://www.cqc.org.uk/sites/default/files/20141208\\_complaints\\_matter\\_report.pdf](http://www.cqc.org.uk/sites/default/files/20141208_complaints_matter_report.pdf).

<sup>91</sup> Clwyd A. and Hart T. (October 2013), *A review of the NHS Hospitals Complaints System: Putting patients back in the picture Final Report*, London: Department of Health/ NHS England, located at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/255615/NHS\\_complaints\\_accessible.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/255615/NHS_complaints_accessible.pdf).

The Healthwatch England study found that consumers faced significant challenges, including barriers to knowing where to go to raise concerns; overly complex and overlapping complaint systems; lack of adequate support to make a complaint; and concerns about the accountability of the complaints handling mechanisms.<sup>92</sup> Too much reliance is placed on self-assessment /reporting and:

*‘...more needs to be done to allow the unconstrained voices ....to be heard by local authorities, regulators and providers so that any threats to human rights can be picked up and resolved as early as possible’.*<sup>93</sup>

These concerns all point to the need for national monitoring mechanisms such as the CQC to adopt systems where the procedures for raising concerns are clear, responsive, supportive, open and transparent. In line with the inclusive and person-centered philosophy of the CRPD, inspectors/monitors must focus on the patient voice and empowerment by working in partnership with persons with a mental disability. The SPT guidance already encourages NPMs to meet privately with detained people in their visiting methodology<sup>94</sup> and the ethos of the CRPD would seem to require it. In that sense, the CQC’s current monitoring methodology and its rhetorical commitment to this inclusive approach<sup>95</sup> is to be commended. In line with the SPT guidelines, the CQC seeks to ensure that inspectors do have relevant experience and are appropriately trained to engage with people with a range of mental disabilities. Inspectors must also be able to identify the risks/signs of abuse, violence and exploitation and be guided by appropriate visiting/inspection templates and prompts/aids for discussions with services users.

CQC inspectors aim to make regular visits and be proactive about meeting directly with people with mental disabilities in receipt of health and social care – taking steps to notify service users in advance about inspections/visits and provide them with accessible and timely opportunities to meet inspectors in private. It is important for

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<sup>92</sup> Op cit. pp. 3-4.

<sup>93</sup> Equality and Human Rights Commission (2011) op cit p. 7

<sup>94</sup> Op cit. para. 25.

<sup>95</sup> See for example the CQC’s annual Mental Health Act monitoring reports for accounts of their approach to inspections located at <http://www.cqc.org.uk/content/monitoring-mental-health-act-report> and see also <http://www.cqc.org.uk/content/how-we-do-our-job>.

inspectors to make time to listen to people talking about their experiences and create a supportive environment for voicing concerns. Patients should be encouraged to speak out and be given assurances about confidentiality to counteract any fears about potential recriminations/ backlash. Where there are communication difficulties/barriers, arrangements should be made for appropriate support, especially advocacy provision as persons with mental disabilities should feel and be supported to raise concerns. Advocacy services can help monitors to engage with persons with a mental disability.<sup>96</sup> Monitors can work closely with service users and advocates to uncover any potential abuse/violence/exploitation. In England, the CQC has commented that advocacy provision for detained mental patients can be effective to support people in this way, but provision is still patchy. Advocacy services for mental health and capacity patients are still under-developed and under-resourced and this impedes patient empowerment and involvement.<sup>97</sup> There are also concerns about the health and social care complaints advocacy service - the Patient Advice and Liaison Service (PALS) – in England. The PALS service has been criticized for not providing adequate independent support for patients. There is clearly a need to improve the support for raising concerns/ making complaints across the entire health and social care system.

Research has demonstrated the importance of moving away from protectionist-focused approaches, towards capacity building and empowerment approaches for people with disabilities to combat the risks of violence/abuse.<sup>98</sup> This means ‘*assisting people with disabilities to build and exercise their capacities to prevent, identify, and manage violence and abuse*’.<sup>99</sup> Ensuring that inspectors put people with mental disabilities at the heart of their monitoring and listen to them will go some way towards realizing the potential of Article 16 of the CRPD. As a recent government review of the changes since the Francis Inquiry<sup>100</sup> has emphasized in England: ‘*A strong patient voice is only*

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<sup>96</sup> Laing, J. M. and Murray, R. (2012), *An international comparative review of mental health monitoring systems*, London: Care Quality Commission.

<sup>97</sup> CQC (January 2015), *Deprivation of Liberty Safeguards 2013/14* (London).

<sup>98</sup> Powers, L. E. and Oschwald, M., op cit. pp. 12-14.

<sup>99</sup> Ibid. p. 13.

<sup>100</sup> Department of Health ( February 2015), *Culture Change in the NHS: Applying the lessons of the Francis Inquiry*, Cm 9009, para. 16 located at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/403010/culture-change-nhs.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/403010/culture-change-nhs.pdf)

*heard when the system is actually listening*'. Healthwatch England highlighted similar issues about the way in which patient concerns have traditionally been perceived and handled.<sup>101</sup> The report concluded that steps must be taken to ensure that people's voices are heard in the complaints system and it should always be focused on the needs of the person making the complaint. Monitors such as the CQC must therefore provide accessible information in a range of formats directing people to the relevant complaints systems. It should be readily available in the full range of settings. As well as opening-up their own procedures for complaints, monitors should scrutinize local complaints resolution processes as part of their inspections and aim to provide some national oversight of health and social care complaints. The CQC has taken some remedial action in this respect, but there is still more progress to be made. In the wake of the Francis Inquiry, inspection reports now include a description of the provider's handling of complaints and the fundamental standards include requirements around complaints handling as well as the new duty of candour (see further below).<sup>102</sup> However, a recent CQC report on complaints handling concluded that there is still:

*'...wide variation in the way complaints are handled and much more could be done to encourage an open culture where concerns are welcomed and learned from. Most providers have complaints processes in place, but people's experience is not consistently good'*.<sup>103</sup>

In fact, the House of Commons Public Accounts Committee has been critical of the CQCs own approach to listening to patients, carers and staff, and acting on their concerns. The Committee recognised that, whilst inspectors do take time to talk to patients, staff and carers during an inspection, this may not capture sufficiently representative views and there is a *'risk of placing too much reliance on anecdotal evidence'*.<sup>104</sup> Inspectors/monitors must therefore ensure that they implement a range of approaches and utilize different platforms to capture the voices of service users, carers and staff, for example by supplementing the face-to-face meetings with electronic and

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<sup>101</sup> (2013) op cit. pp. 32-34.

<sup>102</sup> CQC (December 2014), *Complaints Matter*, located at [http://www.cqc.org.uk/sites/default/files/20141208\\_complaints\\_matter\\_report.pdf](http://www.cqc.org.uk/sites/default/files/20141208_complaints_matter_report.pdf).

<sup>103</sup> Ibid. p. 7.

<sup>104</sup> House of Commons Public Accounts Committee Report op cit paras. 11-12.

paper questionnaires/surveys and organizing wider open and accessible consultation events.

- *Cultural and workforce challenges*

The risks to people with mental disabilities have, of course, been compounded by the institutional cultures, regimes and structures operating in many units and facilities, which, as Goffman pointed out in his work on total institutions in the 1950s and 60s, are traditionally closed. Unfortunately, despite the many advancements that have taken place since that time, similar regimes/ cultures are still found in some units/hospitals today. For example, at Winterbourne View hospital, the government acknowledged that *‘a closed and punitive culture ...develop[ed] on the top floor of the hospital. Patients had limited access to advocacy and complaints were not dealt with.’*<sup>105</sup> Whilst changes have been taking place to create a more honest and transparent NHS in the wake of the Francis Inquiry in England, a recent Department of Health report has noted that there is still much more work to be done.<sup>106</sup> There is no doubt that the health and social care system in England is now a very challenging environment in which to work. Staff in any role at any level also need to feel valued and supported to be able to voice their concerns, speak up and be listened to by inspectors/monitors. As Sir Stephen Bubb highlighted in his post-Winterbourne View report:

*‘Frontline staff are being asked to behave differently – to think more often of people as people and citizens with rights (not just patients with problems), to engage individuals or their families in care more, to be aspirational about what people can achieve. Many do – but again, less because of the system than in spite of it, because we are asking them to do so without a great deal of support*

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<sup>105</sup> *Transforming Care* op cit. para. 2.14.

<sup>106</sup> Department of Health (February 2015), *Culture Change in the NHS: Applying the lessons of the Francis Inquiry*, Cm 9009, para. 16 located at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/403010/culture-change-nhs.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/403010/culture-change-nhs.pdf).

*or training, and without incentivising the organisations they work for to make it a priority’.*<sup>107</sup>

The Francis inquiry identified serious failings in care facilitated by a negative culture of blame and defensiveness. The report recommended several key reforms that were necessary to promote a more open and compassionate health care system. The report made it clear that cultural changes are integral to achieving a safer and caring health system. There have been a series of reforms and initiatives since then to promote the necessary changes in ‘*an unprecedented drive to ensure that the NHS is the most open and transparent system in the world on key measures of patient safety and patient experience*’.<sup>108</sup> These include strengthening the protection for ‘whistleblowers’<sup>109</sup> and introducing a new duty of candour in the NHS. This is a new legal duty on organisations to ensure that, when something goes wrong, patients and relatives are informed about it promptly. The CQC has issued new guidance on whistleblowing, strengthened its methodology and designed a more open, responsive and supportive system.<sup>110</sup> It is too early to assess the full impact of these changes, but they are undoubtedly aimed at creating a more compassionate and patient-centered health and social care system.

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<sup>107</sup> *Winterbourne View – Time for Change: transforming the commissioning of services for people with learning disabilities and/or autism* (A report by the Transforming Care and Commissioning Steering Group, chaired by Sir Stephen Bubb –2014), para. 15.

<sup>108</sup> Department of Health (February 2015), *Culture Change in the NHS: Applying the lessons of the Francis Inquiry*, Cm 9009, para. 7 located at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/403010/culture-change-nhs.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/403010/culture-change-nhs.pdf).

<sup>109</sup> ‘Whistleblowing is the term used when someone who works for an employer raises a concern about malpractice, risk (for example about patient safety), wrongdoing or possible illegality, which harms, or creates a risk of harm, to people who use the service, colleagues or the wider public’ – see CQC (November 2013), *Whistleblowing: Guidance for providers who are registered with the Care Quality Commission*, p. 3 located at [http://www.cqc.org.uk/sites/default/files/documents/20131107\\_100495\\_v5\\_00\\_whistleblowing\\_guidance\\_for\\_providers\\_registered\\_with\\_cqc.pdf](http://www.cqc.org.uk/sites/default/files/documents/20131107_100495_v5_00_whistleblowing_guidance_for_providers_registered_with_cqc.pdf)

<sup>110</sup> See CQC (November 2013), *Whistleblowing: Guidance for providers who are registered with the Care Quality Commission* located at [http://www.cqc.org.uk/sites/default/files/documents/20131107\\_100495\\_v5\\_00\\_whistleblowing\\_guidance\\_for\\_providers\\_registered\\_with\\_cqc.pdf](http://www.cqc.org.uk/sites/default/files/documents/20131107_100495_v5_00_whistleblowing_guidance_for_providers_registered_with_cqc.pdf); See also NHS Improvement/NHS England (April 2016), *Freedom to speak up: raising concerns (whistleblowing policy) for the NHS* located at [https://improvement.nhs.uk/uploads/documents/whistleblowing\\_policy\\_final.pdf](https://improvement.nhs.uk/uploads/documents/whistleblowing_policy_final.pdf).



Whilst much has been accomplished already, the recent Department of Health review of changes post the Francis inquiry concluded that there is still more work to be done.<sup>111</sup> As research by The Kings Fund in the UK has identified, bringing about cultural change requires a range of responses at all levels, but particularly from the top. National monitors and institutions, such as the CQC in England, have a key role to play in leading the way for others to follow, by promoting best practice to create healthy cultures, thereby ensuring the delivery of high-quality and patient-centered care.<sup>112</sup> Two of the key characteristics for promoting a healthy culture are: having clear values, as set out in the NHS constitution, with patient-centeredness and responsiveness at their core; and creating a compassionate and supportive environment for staff and patients. These goals are clearly in line with the ethos and aspirations of the CRPD.

The Department of Health review also recognized that:

*‘The most important resource available to the NHS is its staff, and one of the key lessons of the Public Inquiry, but also the work .. of the new, rigorous inspections undertaken by the Care Quality Commission is the importance of listening to staff. When they raise concerns, they very often know when things are not working well, and when care is not safe. In good organisations, staff concerns are listened to and, where necessary, acted on as part of normal operations. In the best organisations, they are singled out for praise for doing so.’<sup>113</sup>*

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<sup>111</sup> Department of Health (February 2015), *Culture Change in the NHS: Applying the lessons of the Francis Inquiry*, Cm 9009, para. 16 located at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/403010/culture-change-nhs.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/403010/culture-change-nhs.pdf).

<sup>112</sup> See The Kings Fund, *Improving NHS Culture* located at <https://www.kingsfund.org.uk/publications/culture-and-leadership-nhs> and The King’s Fund, (2014) *Culture and Leadership in the NHS: The King’s Fund 2014 survey* (London) located at [https://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/survey-culture-leadership-nhs-may2014.pdf](https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/survey-culture-leadership-nhs-may2014.pdf).

<sup>113</sup> Department of Health (February 2015), *Culture Change in the NHS: Applying the lessons of the Francis Inquiry*, Cm 9009, para. 1.43 located at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/403010/culture-change-nhs.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/403010/culture-change-nhs.pdf). Para. 1.43

It cannot be overlooked how important it is for monitors/inspectors to listen to staff and respond promptly and sensitively to their concerns,<sup>114</sup> as well as doing what they can to help guide/train and motivate staff. Inspectors/monitors can work towards achieving this by promoting examples of good practice; disseminating guidance on human rights/care standards and celebrating successes when there is evidence of good quality and compassionate care. Again, the CQC does attempt to approach its monitoring and regulating functions in this open, responsive and inclusionary way and it has introduced new whistleblowing procedures. However, the degree to which it has been successful in translating this approach on the ground remains to be seen. In the light of the Francis Inquiry, the House of Commons Health Committee decided to inquire into complaints and raising concerns within the NHS in 2014. It reported that improvements were needed to professional regulators and complaints processes; and found that there was a lack of confidence in staff about the consequences of raising concerns which has implications for patient care and safety.<sup>115</sup> It is of some concern to note there has been some unease about the extent to which the CQC is effectively responding to staff concerns and implementing the new whistleblowing procedures to protect staff and patients from poor care.<sup>116</sup> Research suggests that regulators in the UK need to adopt a more consistent and integrated approach to whistleblowing to ensure that concerns are properly addressed.<sup>117</sup> Moreover, a survey of NHS staff in the UK by The King's Fund in 2014<sup>118</sup> found that only 40% of NHS staff who responded to the survey were confident that concerns they raised would be dealt with appropriately, and only 37% of doctors and 31% of nurses felt their organization was characterized by openness and

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<sup>114</sup> See *Freedom to Speak Up: An independent review into creating and open honest reporting culture in the NHS* (February 2015) located at <http://freedomtospeakup.org.uk/the-report/>.

<sup>115</sup> House of Commons Health Committee Fourth Report of Session 2014-15 (January 2015) *Complaints and Raising Concerns*. HC 350, paras. 16-21.

<sup>116</sup> See for example Holt, K. (2015) Whistleblowing in the NHS: Time for a public inquiry to tackle problems with bullying, intimidation, and reprisals. *British Medical Journal*, 350 h2300; Jarman, B. (2014) Quality and Safety in healthcare revisited: a challenge to anaesthetists. *Anaesthesia*, 69(6), 531-536; BBC, *NHS whistleblowing 'problems persist'*, 22 September 2014 located at <http://www.bbc.co.uk/news/health-29280108>; and Alexander, M. et al (December 2016) *Who's keeping a lid on "priceless" whistleblower information in our health system – and why?* Located at <https://www.opendemocracy.net/ournhs/minh-alexander-anonymous-pam-linton-clare-sardari/why-is-cqc-ignoring-or-even-suppressing-pri>; and recent adverse media coverage “NHS's first 'national guardian' resigns after two months”, *The Guardian* 8<sup>th</sup> March 2016 located at <https://www.theguardian.com/society/2016/mar/08/nhs-national-guardian-resigns-post-eileen-sills>.

<sup>117</sup> See Savage, A. and Hyde, R. (2014) The response to whistleblowing by regulators: a practical perspective, *Legal Studies*, 35(3), 408-429..

<sup>118</sup> There were 2,030 responses to the survey in total.

honesty. These figures suggest that the official rhetoric does not always match the reality of the experiences of many front-line staff in the NHS. There are clearly numerous factors at play which impact on the confidence of staff in the health and social care inspection /regulatory systems, and this must also be borne in mind by national institutions in their approaches to oversight and monitoring.

#### **4. Conclusion**

There is no doubt that protecting the rights of persons with mental disabilities under Article 16 brings significant challenges for national monitoring. However, by adopting a holistic, open, responsive, preventive and patient-centered approach to monitoring/inspection, progress can be made towards realizing the goal and aspirations of the CRPD. National monitors/inspectors (as organs of the state) have a key role to play in raising awareness of human rights standards, especially UN treaties such as the CRPD, which is relatively young and still unfamiliar. Monitors also have an important role under the preventive CRPD duty to provide clear guidance on best practice – this will help care providers to understand what is expected of them, and let patients/service users know what they should expect from their care givers and providers.

National monitors already designated as NPMs are well placed to take on board the Article 16 monitoring functions. The guidance issued by the SPT already requires NPMs to be independent and competent in the sense of having relevant expertise, resources and preventive visiting methodologies. Their existing mandates enable them to visit a range of facilities, and in some cases, services and ‘programmes’ in the community. There is also considerable overlap between the concepts of ill-treatment and abuse/exploitation/violence. However, the broader scope and reach of Article 16 will require national visiting bodies to adopt an enhanced focus and approach, as well as giving some serious thought to their inspection priorities in the light of the potential increase in the ‘monitored’ population. Clearly, national monitors will need to adopt different strategies to and priorities for their inspection work within the diverse and wide-ranging contexts in which the CRPD operates. Inspectors must also bear in mind the social and political contexts in which they operate, as well as work towards resolving some of the tension in Article 16 with the broader enabling ethos of the treaty. And, of course, last but by no means least, the key issue will be for national

governments to ensure that monitors are adequately resourced, in both human and financial terms, to meet the additional demands that CRPD related monitoring would entail.

There is no doubt that the CRPD is aspirational in nature and considerable expectations would seem to be placed for independent monitoring in the context of Article 16 to provide protection. One thing is clear, change cannot be achieved by national monitoring bodies alone – they must work in tandem with national governments and authorities; health and social care providers; patients/ persons with a mental disability, and their families/carers; advocacy groups and civil society to ensure that the voices of persons with mental disabilities are heard and, more importantly, listened to. As other scholars have identified in the context of the OPCAT obligations, *‘many other factors come into play in determining whether it has any impact on the ground’*.<sup>119</sup>

The recent Department of Health review of the NHS post the Francis Inquiry has stressed that the key challenge moving forward is recognizing that new values must be embedded in education and training for all workers: *‘regulation is just one part of the solution: there also needs to be cultural change so that these standards are intuitive’*.<sup>120</sup> There are some signs that the climate in the NHS in England is changing and moving (albeit slowly) towards a more open, patient-centered and compassionate service where *‘patients [are] in the driving seat for any decisions taken about them’*.<sup>121</sup> Although this article has also highlighted that there is no room for complacency and much more work left to be done. Nonetheless, the CRPD is very much aligned with these goals within the NHS and it requires a similar shift in attitudes and approach - to put people with disabilities at the heart of all decision-making about their lives too. We can only hope that the government and state actors such as the CQC harness the opportunities that the CRPD brings at a time when universal change is most needed. According to the British Red Cross, the health care system in the UK is currently under so much pressure that it

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<sup>119</sup> Murray R. et al (2011), *The Optional Protocol to the UN Convention against Torture*, Oxford: OUP, p. 137.

<sup>120</sup> Department of Health (February 2015), *Culture Change in the NHS: Applying the lessons of the Francis Inquiry*, Cm 9009, located at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/403010/culture-change-nhs.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/403010/culture-change-nhs.pdf).

<sup>121</sup> Ibid.

is facing a ‘humanitarian crisis.’<sup>122</sup> Hence, the need to empower, engage with and listen to people with mental disabilities to ensure they receive safe, dignified, inclusive and equal treatment is even more pressing:

*What is critical now is that leaders throughout the NHS keep the memory of what occurred fresh in their minds and are inspired by the progress that has been made as new challenges emerge. Good use of resources will always be critical... but it must always be remembered that they are the means to an end – safe, effective, respectful and compassionate care for **all our citizens**.*<sup>123</sup>

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<sup>122</sup> See ‘Britain’s Health Service in a ‘humanitarian crisis’ – Red Cross’ located at <http://uk.reuters.com/article/uk-britain-redcross-health-idUKKBN14R08H>.

<sup>123</sup> Department of Health (February 2015), *Culture Changes in the NHS: Applying the lessons of the Francis Inquiry*, Cm 9009, para. 5.3 Located at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/403010/culture-change-nhs.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/403010/culture-change-nhs.pdf) (Emphasis supplied)

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